

Testimony in Support for House Bill 6200

TO all our Public Health Committee Members:

I wish to stress the need for protection for doctors who treat this disease aggressively. My daughter contracted lyme disease and Bartonella disease in October of 2007. Her symptoms started out as headaches. She was treated by her pediatrician for migraines. When that did not work, we tried amoxicillin for 10 days for a sinus infection. Her symptoms went away for a couple of days. Then they came back along with many others-including muscle aches, joint pain, and fatigue. The pediatrician did a lyme test but it came back negative (maybe because of the antibiotic use). We were sent to a neurologist who did not think it was lyme but ran a battery of tests. Nothing came back positive. She also sent my daughter for a MRI. By now it is the middle of December and we still have no diagnosis. I truly felt she had lyme. At this point I made an appointment with a doctor in New York who has been known to treat lyme even though he is out of my network for insurance. He ran a battery of blood work and the tests came back positive for lyme and Bartonella. He treated her for three months with oral antibiotics. Her symptoms disappeared for 8 months. She is now had a relapse and we are back at this doctor. She had some improvement at first but now we are changing her antibiotics. It is costing us quite a lot of money because he is out of network. As I understand it from others, all the doctors who will treat lyme do not take insurance because they are afraid of being disbarred.

Please understand that, yes, some people only need to be treated for a month or 6 weeks but those especially with co-infections have a harder time getting rid of the infection. The problems has many issues: including doctors not testing for them, the test used are not adequate, doctors not understanding the disease, and not giving the antibiotics for a long enough time.

If you know anyone who has gone through or is still dealing with this disease, you would understand. Since my daughter contracted lyme, I have met several people with long term cases of this disease. One woman still has symptoms after being on antibiotics for over a year; she has improved from being on her death bed, a functioning member of society but still struggling with symptoms. Another has been on medication for over 20 years, because every time she goes off the medication her symptoms return.

I am very scared for my daughter. I hope that she does not have a chronic case of lyme and that the doctors can find the right combination of medication to eradicate it from her body. She is in her senior year of high school and she is tired of being sick, especially for a second time. Her symptoms are getting worse and more have appeared in the last couple of weeks. She has fatigue, muscle aches, joint pain, headaches, eye pain, chest palpitations, eye pain and the worst is the problems with concentration. School is a struggle. Last year she missed about 15- 18 days of school because of it. This year she missed about 6 so far (because she recognized the symptoms returning) but every time the medication changes there is the risk that symptoms get worse before there is improvement because the bacteria are fighting back. And we will be changing it again.

After speaking with her math teacher yesterday, he said he know of about 20 students with lyme.

Please understand the struggles we have gone through to get proper treatment for our daughter. We had to go to a doctor who is almost an hour away. At some point she may need IV

antibiotics because the doctor believes the lyme is in the brain. Some of the lab work is covered by my insurance but not all of it. The doctor visits are not until I reach a number in the thousands.

Thank you for your time and consideration of this issue. I am sure you would understand how important this issue is if it was one of your family members.

Sincerely,

Elizabeth Smith
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